Remarks of U.S. Representative Edward J. Markey American Psychoanalytic Association "Congressional Staff Breakfast Discussion"

May 14, 1999

I would like to begin by thanking Dr. Bob Pyles for asking me to be here today to say a few words on what I believe is one of the greatest threats to our health care system today. The growing lack of medical privacy which threatens the very heart of quality health care -- doctor/patient confidentiality. By undermining this sacred relationship between doctor and patient, we destroy the trust that patients rely on for peace of mind, and providers depend on for sound judgment.

Today doctor/patient confidentiality is rapidly eroding. With the stroke of a few keys on a computer or the swipe of a prescription drug card, our personal health information is being accumulated and tracked.

In an HMO today, anywhere from 80-100 employees may have access to a patient's medical record according to the Privacy Rights Clearinghouse in San Diego California. With such unrestricted access to one's personal health information, it's impossible to separate the health privacy keepers from the "just curious" peepers.

Not to mention the information reapers.

The evolution of technology has provided the ability to compile, store and cross reference personal health information, and the dawning of the Information Age, has made your intimate health history a valuable commodity.

Last March, the Wall Street Journal wrote about the ultimate information reaper -- a company that is "seeking the mother lode in health 'data mining'". This company is in the process of acquiring medical data on millions of Americans to sell to any buyer.

As you now know, thanks to this briefing, we have no federal medical privacy law to constrain the information reapers as they delve into large data bases filled with the secrets of millions of individuals. These data bases represent a treasure chest to privacy pirates and every aspect of your medical information represents a precious jewel to be mined for commercial gain. With unfettered access, patient confidentiality has become a virtual myth, and the sale of your secrets a virtual reality. Because of the rapid evolution of technology, we have fallen behind in assuring a right that we have come to expect—the fundamental right to keep our personal health information private.

This is why last March, I along with Representatives Mc Dermott and Strickland introduced the Medical Information Privacy and Security Act in the House, while Senators Leahy and Kennedy introduced the Senate version.

Our bill creates an incentive to use information which is not personally identifiable wherever possible, it would require a warrant for law enforcement to access medical records, it would provide a federal floor creating a uniform standard without preempting stronger state laws and finally it would provide for a patient's

informed consent. And let me take a moment to spell out what informed consent means to me in three words: Knowledge, Notice and No.

I believe patients have a right to the knowledge that health information will be disclosed for treatment purposes at the onset of treatment.

I believe patients have the right to notice if their personal health information will be used for any purpose other than that directly related to their treatment —

And finally when patients are given notice that their information may be disclosed for anything outside of direct treatment, they should have the opportunity to say NO without losing their coverage.

It's a simple formula but it's a right we as patients deserve.

In closing, I would like to thank the American Psychoanalytic Association for endorsing The Medical Information Privacy and Security Act. Working together, I believe we will succeed in passing a strong federal medical privacy bill which will give patients the right they deserve – the right to medical privacy.

I thank you.